



White paper

Patient centricity: What it means and why it's important to have patients at the centre of our thinking

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EXECUTIVE SUMMARY

Boehringer Ingelheim UK has set itself the challenge of measuring the extent to which it embraces the patient voice throughout its business processes. It is pioneering a self-scoring system of a few core principles of patient-centric engagement that it hopes will demonstrate year-on-year that it is moving in the right direction. This is no easy task but the advantages are wide-reaching. Externally, such a benchmarking system will give patient and carer organisations a clearer idea of what the company stands for and the direction in which it is headed. Internally, it will reinforce this profound and necessary change in direction to reflect an NHS exemplified by the phrase “no decision about me, without me” and set new horizons that help realise this laudable goal.



The meaning of patient-centricity

Patient-centred thinking may not seem particularly revolutionary to anyone outside healthcare. But it is a notion that is slowly but surely transforming how medicines are conceived, trialled, delivered and reimbursed. It can be seen in a number of ways, such as seeking patient input on whether a clinical trial protocol makes it easy or hard to participate, or involving patients in the design of medicine packaging. The key stakeholders in all this, the patients, are probably unique in *not* thinking in terms of patient-centricity. Nevertheless, their voice, their involvement in treatment plans, their experience of those plans and, most importantly, their outcomes are gaining significant traction as everyone tries to work out what it means to put the patient rather than the system first in healthcare.

The roots of this transformation are well documented. Partly, they are to do with the fact that patient outcomes can now be measured more effectively and are therefore more important to reimbursement and access decisions than ever before. Partly, they are to do with patients having access to the internet and therefore more opportunity to be informed and take control of their healthcare. And partly, they are to do with healthcare reforms on both sides of the Atlantic that strongly incentivise providers to put patients at the centre of healthcare decision-making.

The UK government's consultation document, ['Liberating the NHS: No decision about me, without me'](#), published in May 2012, is an example of the change in thinking at governmental level. Indeed, this document was instrumental in confirming that Boehringer Ingelheim UK was on the right track in its early efforts to become more patient-centric. In particular, the title phrase, "no decision about me, without me" became the starting point of a major internal initiative known as 'Painting Boehringer Ingelheim's Future'. This involved canvassing internal views from a range of teams including sales, marketing, medical and health policy, as well as seeking external input from patient groups, carers and NHS leaders to try to understand how the landscape would evolve as a result of the NHS changes and what would need to be done as a company in response. On the publication of NHS England's ['Five-Year Forward View'](#) in October 2014, the initiative's central steer evolved further to incorporate the document's emphasis on empowering patients and engaging communities.

What patient-centricity means to pharma companies

The May 2012 NHS document provided a definition of patient-centricity. "Patients should be at the heart of everything we do," it said. "Genuinely shared decision-making is about giving everyone more say in decisions about their own care. It's about being sensitive to people's preferences and aspirations for their care and treatment and it's about having the right information to make informed decisions, supported by professionals."

This definition may be broadly accepted for providers but what patient-centricity means to pharma companies, with their traditional focus on products and prescribers, remained unclear. The 'Painting Boehringer Ingelheim's Future' initiative, which was led by a team including the managing director, medical director, marketing director and communications director, led to two realisations. One was that the company needed to embrace patients and carers at a deeper level in how it develops, and communicates about, medicines. The second was that it needed a deeper understanding of what was expected of it by patient and carer organisations to have any chance of delivering on that. As a result, the Public Affairs and Patient Advocacy team was created to represent all the therapy areas the company invests in and to evolve a more strategic approach to its work with patients and carers.

This was an important structural change because prior to this the company had been doing a lot of good work with patients and carers by, for example, simplifying the materials it produces for them and ensuring it interacts at every opportunity despite the complicated regulations governing how pharma can do that. But it had been a piecemeal approach with people from market access, marketing, health policy and medical all coming at it from very different angles.

The most critical learning from this exercise was that while the company had made progress in listening to and working with patients and carers it needed to benchmark what it was doing. It needed clear measures that could demonstrate progress both internally and externally. That was the kernel of the idea to create a method of scoring our efforts to be truly patient-centric.

Immediately following this, a survey of a number of different types of stakeholders was commissioned, which has been repeated over the past couple of years, to get a feel for how Boehringer Ingelheim UK is perceived both generally and specifically in relation to its work with patients and carers. The results were positive with one department director at the Department of Health volunteering, for example, that “[the company has] probably moved faster than others in terms of changing from a traditional sales force to a more insightful group of individuals doing market development. They try hard to align to the value proposition of patients.”

The need for a scoring system

In an effort to understand more deeply what should be measured, the patient organisations the company works with were asked what pharma patient-centricity means to them. The one thing they all agreed on was that while it was easy to talk about being patient-centric it was much harder to ‘walk the talk’, confirming the need for a benchmarking tool that can demonstrate internally and externally that the company listens to, and takes action on, the views of patients and carers.

The idea was that it would act as a transparent ‘shop window’ for patient organisations thinking of partnering with Boehringer Ingelheim UK, as well as evidence for its employees that they are working for an organisation that gives as much focus to patients as it does to doctors. Perhaps most importantly, however, having clear parameters of patient-centricity that can be measured year-on-year enables the company to know if it is moving in the right direction and to set targets for what it hopes to achieve in the future.

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What patient-centricity means to patient and carer organisations

What the patient organisation representatives revealed was as encouraging as it was insightful, especially as many have been through similar exercises themselves. Steven Wibberley, chief operating officer at the [British Lung Foundation \(BLF\)](#), for example, pointed out while it’s about having the needs of patients at the centre of every activity and making sure those activities are focused around improving outcomes, it is extremely difficult to deliver on this. “How do we know what outcomes are important for patients, and how do we engage with patients so that the way we work to meet those outcomes is as informed and driven and steered by patients as possible?” he asked. “This is not easy for an organisation like ours let alone for a pharmaceutical company.”

The challenges, he went on, are about getting the balance right between the time spent engaging and listening to patients to understand their needs versus getting on and doing the work. “Are the primary needs around understanding what causes the disease so you can support research around a cure or is it about the impact that disease has on their lives, so the work is around mitigating the impact it has on their lives?”

The difficulties are compounded, he added, because not only are there around 40 different respiratory diseases but the experience of a family with a young child with a respiratory condition is very different from that of an elderly person who has smoked all their lives. “There is no single perspective so how do we decide on that balance?”

The BLF, he explained, has a network of 230 local self-help groups of people with respiratory conditions. These groups act as intermediaries to help shape its activities much like the BLF and other patient organisations work with pharma companies. “Because of this complexity all one can say is are we doing things that are going in the right direction to better understand and respond to the patients? In that sense I would say we’ve still got a long way to go.”

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Conal Presho, head of corporate partnerships at [Asthma UK](#), meanwhile, said patient-centricity is around ensuring the views and needs of patients are embedded in the planning stages and throughout a medicine’s development. “It has been a long process to be able to confidently reflect the general patient voice,” he says. “In the past, there were a few loud voices that dominated the conversation but we have worked hard to reflect a broader constituency.” His conclusions are that the most important things in upholding patient-centricity are, one, being open to being challenged by patients and, two, being able to demonstrate not only that those challenges have been heard but that this has resulted in some kind of change.

One message that was heard repeatedly was that patients and carers should be as central to a company’s thinking as the need for profit, permeating and informing all aspects of the business. Therefore, pharma must provide not only information about clinical trials, for example, but also understand the issues involved in measuring quality-of-life outcomes and the patient perspective within that. A direct connection between patients and industry is a step too far; what’s needed is an organisational consciousness of the patient experience, manifested in early engagement and a collaborative approach with all stakeholders to identify key priorities.

Beyond the patient

Madeleine Starr, director of business development and innovation at [Carers UK](#), highlighted the efforts of the UK’s 6.5 million carers to support patients and said true patient-centricity is about ensuring their needs are also taken into account. “It is about making sure the patient gets the maximum possible benefit from a medicine and that also involves the carer, because medication management is as much about the individual who is helping to support that care pathway as it is about the patient,” she said.

“There are many things companies can do once they start putting themselves in the shoes of patients and carers and thinking about what would improve their experience of their condition.”

She went on to explain that means ensuring patients can tolerate the medicine, it can be administered easily, it is taken at a time of day that is easy to remember and its benefits and risks are clearly communicated. “It may also be about encouraging hospitals to provide medication information packs on discharge, outlining five points patients and carers need to remember when this medication is taken. There are many things companies can do once they start putting themselves in the shoes of patients and carers and thinking about what would improve their experience of their condition.”

The fact Boehringer Ingelheim UK is a member of the charity’s Employers for Carers forum was evidence, she added, of its commitment to embracing the patient experience. This helps employers support its staff who are also carers by, for example, subscribing to the charity’s care coordination app, *Jointly*, a simple communication tool that enables family members and carers to know how a patient is being looked after at all times. Boehringer Ingelheim UK is currently helping to fund a focus group to improve the medications management feature of this app as it has proved so popular with carers.

Listening and hearing

When patient representatives were asked what principles should underpin Boehringer Ingelheim UK's engagement with them, they were unanimous in saying that companies need to not only listen but also hear what is being said.

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Patient organisations have various ways of informally gauging whether companies do that. One is how people talk about patients and carers. Another is about seeking early communication about medicines on the horizon and seeking input and support around the priorities that enable a treatment to be of maximum benefit.

Ideally, collaborations with patients and carers should be long-term, have a shared objective and where both sides have made significant investments. It is not just about the pharma company providing money, in other words, but both sides contributing in terms of people, time, enthusiasm and ideas as well as money. The following case studies are examples of current or recent Boehringer Ingelheim UK collaborations.

Case study

Raising awareness of idiopathic pulmonary fibrosis (IPF)

Opportunity: IPF is a rare and terminal lung disease that had been identified by the BLF as one of its top five strategic priorities. In particular, the charity wanted to raise awareness of the condition so people can be correctly diagnosed earlier.

Joint working: Boehringer Ingelheim UK jointly funded a project manager within the charity to focus on IPF and supported that person to organise a range of activities including a series of 'Meet the Expert' events for patients, carers and healthcare professionals to understand more about the condition. The two organisations facilitated qualitative market research via video diaries to highlight the difficulty in getting an accurate diagnosis. This research helped inform information materials produced by the charity. Ongoing work on the part of Boehringer Ingelheim UK includes lobbying MPs in constituencies where there are specialist facilities to treat the condition using a report called 'Lost in the System' published by the charity.

Verdict: "The company was genuinely interested in the experience of IPF patients, which was made evident by the fact they were prepared to fund the research and then continually refer back to that research and demonstrate it had influenced their thinking around that disease and patient group," said Wibberley of the BLF.

Case study

Asthma Action Plan Review project

Opportunity: A recent national review of asthma deaths had highlighted the poor care received by people with asthma and, in particular, that many of the people who died unnecessarily after a flare up of their condition did not have an action plan spelling out best practices in terms of what to do in such circumstances and ensuring patients know how to use their inhalers properly as well as regularly.

Joint working: Boehringer Ingelheim UK had funded an earlier 'Compare your Care' campaign, which was a research study to compare levels of care patients receive from primary and secondary care and whether they had an action plan. This revealed a huge amount of variation. As part of a regular dialogue between the two organisations, Boehringer Ingelheim UK expressed an interest in working on this latest project to ensure people know the importance of having an action plan. It began in June 2014 and is fully funded by the company.

Verdict: "Boehringer Ingelheim are very engaged," says Conal Presho of Asthma UK. "It is constantly working with us trying to find new projects and finding out what we are doing. It is one of our most committed corporate partners."

The Boehringer Ingelheim UK team's perspective

Prof. Klaus Dugi

Medical Director, Boehringer Ingelheim UK

No pioneering project is easy. Internally, we knew we wanted the principles of engagement and its scoring system to be appropriate and personal to Boehringer Ingelheim UK. We also knew it should align with the company philosophy and, where possible, deploy a bottom-up approach. We didn't want to compare ourselves to other organisations; nor did we want a set of measures that are arbitrarily defined by other people. What is right for Boehringer Ingelheim, as a mid-sized UK company, will be our aspiration to achieve our goal with some effort.

We're part way through a journey to address this. We are currently agreeing the scoring system with the aim to start 'scoring' in the second half of this year. It will not necessarily be based on numerical targets. It could be that being patient-centric means the company conforms to The Information Standard, for example, which means any patient-facing materials have been read by a panel of representative patients who can confirm it is useful, relevant and understandable, and most importantly suggest changes and recommendations when the materials fail to meet this standard. This is already being piloted on our online communications on a few of our medicines and it is a clear demonstration of our commitment in that it involves finding a patient panel, seeking input, and then making changes to the materials in accordance with that panel.

The aim of the project is not to put patients ahead of medicines *per se* because ultimately the job of a pharma company is to create innovative medicines that help people. Rather, it is to demonstrate the company is meeting its own expectations and those of patients and carers in terms of hearing and acting on what patients and carers are saying. By having clear benchmarks that are revisited year in, year out we expect to be able to demonstrate internally and externally that the company is moving in the right direction and to set new goals.

Prof. Klaus Dugi

Klaus first joined Boehringer Ingelheim in 2003 to translate the pre-clinical diabetes pipeline into clinical research. Klaus



is an internist and endocrinologist by training and prior to joining Boehringer Ingelheim, he was heading the Metabolic Outpatient Clinic at Heidelberg University Hospital where he continues to teach Internal Medicine.

Klaus also spent four years in the US conducting research at the National Institutes of Health in Bethesda, Maryland.

During his more than 12 years at Boehringer Ingelheim, Klaus has served roles in Clinical Operations and Clinical Development and held the positions: Head of Global Medical Affairs; Therapeutic Area Head, Medicine Metabolic Diseases; and Chief Medical Officer. He took on the role of Medical Director for the UK and Ireland in August 2015.

Conclusions

Patient-centricity is often used as a buzz-phrase that few people can define, let alone measure. Boehringer Ingelheim UK has therefore taken on the challenge of setting its own benchmarks on what it means to be patient-centric and how it can be achieved, the details of which and the 2015 'score' will be outlined in a follow-up white paper due later this year.

“Patient-centricity as a core business principle is a triple win because it is good for business, good for patients and carers, and also good for healthcare systems.”

In establishing such a pioneering system the company plans to communicate regularly and transparently what it stands for and deliver concrete evidence of its patient-centric credentials implicit in its activities and the impact of those activities. By keeping a year-on-year tally of those credentials it will be able to show if it is moving in the right direction in reflecting the patient voice and also set new, more ambitious, goals for the future.

As a company, we believe this is the right direction and our thinking is summed up well by Madeleine Starr of Carers UK when she says patient-centricity as a core business principle is a triple win because it is good for business, good for patients and carers, and also good for healthcare systems. What we are doing, in short, is saying “this is how we do business and we do business like this because we think it’s the right thing to do and because we believe in these defined core principles of patient-centricity”.

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- **Conal Presho**, Head of Corporate Partnerships, Asthma UK
- **Madeleine Starr**, Director of Business Development and Innovation, Carers UK
- **Steven Wibberley**, Chief Operating Officer, British Lung Foundation



About the author: Duncan Cantor

Boehringer Ingelheim

Boehringer Ingelheim is a family owned company. We have a distinctly independent structure, which means that we are not constrained by the needs of shareholders. This means that for the last 130 years we have been able to focus on the future and invest in our own research and development.

We provide treatments for a range of long-term and acute diseases and consistently reinvest over 20% of our net sales in researching new and innovative medicines in areas of high unmet need.

This investment in R&D has been the foundation of our success. It has helped us discover and develop new medicines for humans and animals that improve lives.

Duncan Cantor is the UK and Ireland communications director for the family-owned pharmaceutical company Boehringer Ingelheim.

Since joining Boehringer Ingelheim in 2008 he has held government affairs and communication roles in the UK and globally. Working across sectors and roles has given Duncan a distinct perspective on patient engagement in healthcare, and through his career in Boehringer Ingelheim, Duncan has worked on projects and initiatives that have focused on putting the patient front and centre in the company's thinking.

Prior to his current role, he worked in sectors including banking and private healthcare.

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